



UBC CENTRE FOR
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Measuring Patient Experiences in Primary Health Care

A review and classification of items and scales used
in publicly-available questionnaires

May 2013



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a place of mind

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About CHSPR

The Centre for Health Services and Policy Research (CHSPR) is an independent research centre based at the University of British Columbia. CHSPR's mission is to advance scientific enquiry into issues of health in population groups, and ways in which health services can best be organized, funded and delivered. Our researchers carry out a diverse program of applied health services and population health research under this agenda. The Centre's work is:

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About the Canadian Primary Health Care Research and Innovation Network (CPHCRIN)

Established in October 2011, CPHCRIN is a research, training, and knowledge exchange network whose vision and operations are informed by an understanding of the contribution to performance and capacity building that can be made by a pan-Canadian research network, and by an inclusive approach. The network acts as a rich heterogeneous forum that yields creative discussion and debate about the future of CBPHC in Canada, and that allows us to better address the pressing challenges of today with a research agenda that encompasses a vast number of questions, perspectives, and methodologies. CPHCRIN facilitates the creation, translation, and scale-up of innovative models of CBPHC, in order to influence the efficiency and effectiveness of health care in Canada.

For more information about CPHCRIN please visit www.cphcrin-rcrissp.ca.





Forward

The Canadian Primary Health Care Research and Innovation Network (CPHCRIN) is pleased to host three important and related scoping reports on measurement in primary health care (PHC). Measurement is basic to organizational quality improvement, reporting, and accountability and research to improve our understanding of primary health care (PHC) service delivery. Stakeholders, including decision-makers, clinicians, and researchers, very often need to collect data that is best reported by practices, clinicians, and/or patients to answer practice and research questions.

There are three separate but related technical reports that are companions to the Canadian Institute for Health Information (CIHI) suite of PHC organizational, provider, and patient experience surveys. The authors of these three reports scanned international scientific and grey literature to bring together the many varied ways different people have tried to measure the delivery and experience of primary care service. The organizational and provider reports bring together, for the first time, information on different dimensions of PHC best reported on by organizations or clinicians. The patient report updates and builds on work that examined patient experiences in PHC. All authors have reviewed and classified measurement items and scales used in publicly-available questionnaires. CIHI also sought feedback from stakeholders on the development of the suite of surveys.

This work is the first step in preparing a suite of new PHC surveys that captures dimensions of PHC important to Canadians. The hope is that these surveys will be widely adopted and used. Standardized surveys bring the advantage of allowing comparisons with work done by other jurisdictions in other contexts. CPHCRIN encourages researchers and other stakeholder groups to use, where ever possible, the resulting new suite of surveys. Should it happen that your particular area of enquiry is not fully addressed in the new surveys, these reports will provide you with a comprehensive list of tools or indicators which might better address your particular need. It is expected that these scoping reports will save you time as they present the many different ways questions have been asked to try to understand PHC service delivery.

CIHI provided financial and staffing support for this work. The final suite of three new surveys is available on the CIHI website at www.cihi.ca/phc.

Sincerely,

A handwritten signature in black ink, appearing to read 'William Hogg'.

Dr. William Hogg
on behalf of the CPHCRIN Executive Committee

Executive Summary

Monitoring information about patients' experiences is essential to stimulate innovation, track changes in quality, and help Canadians become more informed about their health care system. Measuring the quality of the primary health care (PHC) system from patients' perspectives has been identified as a crucial step towards defining areas of improvement and monitoring the impact of change. Regularly scheduled PHC surveys have been recommended as a future data collection strategy. However, no standardized, self-reported or comparable PHC survey currently exists for use with patients across Canada.

The purpose of this review was to identify items and scales to inform the composition of a core Patient Experience Survey for use across Canada. This scoping review provides an up-to-date review of the publicly available instruments that purport to measure patients' experiences in PHC.

The three main objectives of this review were to:

1. Identify the relevant instruments and surveys assessing patients' experiences in PHC;
2. Classify items and questions in the appropriate dimensions of patient experiences; and
3. Provide a foundation for the Patient Experience Survey instrument for the Canadian Institute for Health Information (CIHI) Primary Health Care Survey project.

The Patient Experiences Survey was developed based on a review of relevant conceptual frameworks related to performance measurement of the PHC system, and past work that provides operational definitions of dimensions relevant to PHC from patients' reports of their PHC experiences. Relevant instruments and surveys were assessed based on previous work, an

environmental scan of health surveys completed by CIHI and a review of national and international the peer-reviewed and grey literature. Items for inclusion in the Patient Experience Survey were based on two criteria: 1) relevant to patients' experiences in PHC and 2) publicly available. Instruments and surveys published in English and French were reviewed.

A total of 17 instruments and surveys were retained. The instruments varied in size as did the number of dimensions and sub-dimensions. The Patient Experience Survey measures six dimensions (15 sub-dimensions) of PHC that are best measured based on patient reports: 1) Access, 2) Interpersonal Communication, 3) Continuity and Coordination, 4) Health Promotion within Technical Quality of Care, 5) Trust, and 6) Patient-Reported Impacts of Care.

This work highlighted that many surveys and instruments exist to assess patient experiences in PHC and that no instrument or survey offered full coverage of dimensions of PHC important to patients. The items used to develop the Patient Experience Survey are meant to capture various aspects of how the PHC system is performing. This Patient Experience Survey contains items that measure outputs and immediate outcomes of PHC that are best reported by patients. The immediate outcomes of PHC are considered patient-reported impacts of PHC delivery.

The length of the survey administered to patients will depend ultimately on the dimension and sub-dimension of interest and the purpose for which the survey is being conducted. Therefore, choosing dimensions and sub-dimensions of interest, rather than specific items, should be identified prior to survey administration.



1. Introduction

1.1. Contribution of Patient Experiences in Primary Health Care (PHC) to the Performance of Health Care Systems

Health care systems with a strong foundation of primary health care (PHC) are recognized for improving the overall health of populations.^[1-3] To improve access to health care for Canadians, decision-makers have made a number of commitments supporting the reform towards the organization, financing and delivery of PHC.^[4, 5] By focusing on access to services, continuity of care, effectiveness, safety, responsiveness and comprehensiveness^[2, 3, 6] in PHC, it is expected that patients would report a great impact on their health.

Monitoring information about patients' experiences is essential to stimulate innovation, track changes in quality, and help Canadians become more informed about their health care system.^[7] A well-constructed PHC survey offers a window into patients' perceptions that is otherwise unavailable.^[8] Patients are uniquely positioned to report on their care experiences and they are often the only common thread across disparate health care settings.^[9] Consequently, measuring the quality of the PHC system from patients' perspectives has been identified as a crucial step towards defining areas of improvement and monitoring the impact of change.^[10] Regularly scheduled PHC surveys have been recommended as a future data collection strategy.^[11] However, no standardized, self-reported or comparable PHC survey currently exists for use with patients in Canada.

1.2. Developing a Tool to Measure Patient Experiences in PHC

The Canadian Institute for Health Information (CIHI) led the development of a suite of three survey instruments for PHC organizations, providers and patients

that can be used to measure performance of PHC. This scoping review was part of the Primary Health Care Survey project of the CIHI and was done in order to support the creation of the patient experience questionnaire that could be used to assess the quality and performance of PHC in Canada. The purpose of this review was to identify survey elements to inform the composition of a core patient experience survey instrument that could be used across Canada.

In Canada, research in primary health care has not fully utilized patient reports of their experiences.^[12] Patients who have ever used PHC offer valuable contributions to the improvement of their care. They can be definers of good quality, evaluators of health care delivery and reporters of their experiences.^[13] As participants in health care delivery, they can influence the quality of care in more direct ways, such as involvement in decisions concerning medical treatment. Patients' perspectives for assessing the quality of care focuses on aspects of service delivery important for patients.^[14, 15] Ongoing monitoring of patients' experiences using self-report surveys combined with routine feedback to PHC providers can lead to practice improvements and internal quality control; it also enhances a culture of patient engagement.^[16] Engaging patients increases the likelihood that they can carry out agreed-upon treatment plans to the best of their abilities. Patients who are engaged in understanding their condition are more likely to report a better quality of life and satisfaction with PHC.^[17] Outcomes of ongoing monitoring and feedback include enhancing patient choice of provider, better adherence to medical advice,^[18-20] and reduced rates of complaints,^[21] grievances,^[22] and the level and seriousness of malpractice claims.^[23, 24] It can affect functional health outcomes and actual health.^[16, 19, 25, 26]

Some developed and validated self-report PHC instruments have been used in Canada, but no single instrument captures all dimensions of the quality of PHC important to patients. Two instruments used commonly to measure the quality of PHC in Canada are the Primary Care Assessment Tool (PCAT)^[27] and the Primary Care Assessment Survey (PCAS).^[28, 29] The PCAT^[27] consists of five PHC domains: strength of affiliation with provider, first contact (accessibility and use), ongoing care (relational longitudinality), comprehensiveness (availability and provision of services), and coordination (medical record continuity and integration of care). The PCAS^[28, 29] contains seven PHC domains: accessibility (financial and organizational), continuity (longitudinal and visit-based), comprehensiveness (contextual knowledge of the patient and preventive counseling), integration, clinical interaction (physician-patient communication, thoroughness of examination), interpersonal treatment, and trust.^[30-32] Both of these instruments are long and measure different dimensions of PHC.

Other self-report generic PHC instruments such as the Components of Primary Care Index,^[33] the EUROPEP,^[34, 35] and the Ambulatory Care Experiences Survey (ACES)^[8] have been shown to be valid for Canadians, and have been translated into French. None of these instruments have been validated for other languages commonly spoken in Canada such as Chinese or Punjabi. There are several distinctions between instruments, but the biggest issue is that the use of different instruments makes it very difficult to compare patient experiences over time or between regions. Development of a reliable and validated Canadian PHC instrument will provide a standardized measure that can be used to monitor the quality of the PHC system from the patient perspective.

Since 2000, there has been considerable interest in collecting patients' perspectives on health and health care. There are existing surveys collecting PHC information, including the Canadian Community Health Survey (CCHS),^[36] the Health Services Access Survey (HSAS),^[37] the Canadian Survey of Patient Experiences with Primary Health Care (CSE-PHC)^[38] and the Commonwealth Fund International Health Policy Survey.^[39] The CCHS is a population-based survey, administered by Statistics Canada using both computer-assisted personal and telephone interviews every two years, that collects a broad range of health information.^[36] The HSAS is a supplement to the CCHS. The HSAS is conducted at irregular intervals, designed to collect information on patient experiences of access to first contact services and waiting time for key diagnostic and treatment services.^[37] The CSE-PHC was conducted in 2007 with a nationally representative Canadian sample.^[38] The Commonwealth Fund International Health Policy survey is a yearly survey conducted in Australia, Canada, New Zealand, the U.K., and the U.S.^[39] It collects information on access, emergency care, coordination, continuity, and consumer-physician interactions, but these data are not publicly available for research or planning use.

1.3. This Report

This scoping review provides an up-to-date, international review of the publicly available instruments that purport to measure patients' experiences in PHC. We provide a classification grid of the different dimensions currently measured in these surveys and classify the items and instruments that measure different dimensions. The survey tools reported here help us to elaborate a more complete set of measures in order to allow users to capture many dimensions of patient experiences relevant to PHC.



2. Objectives of the Review

This review aims to draw a global portrait of the main items and question formulations found in instruments that can be used to measure patient experiences relevant to PHC. The three main objectives of this scoping review were:

1. To identify the relevant surveys and tools assessing the patients' experiences in PHC;
2. To classify any single items and questions in the appropriate dimensions of patient experiences.
3. To provide a foundation for the Patient Experience Survey Instrument for the CIHI Primary Health Care Survey project.

3. Methodology

The Patient Experiences Survey was developed based on a review of relevant conceptual frameworks related to performance measurement of the PHC system and past work that provides operational definitions of dimensions relevant to primary care^[40] and patients' reports of their experiences in PHC.^[41, 42] We developed a pool of relevant items that could be used to measure dimensions of PHC best reported by patients. Once the survey was constructed, we used cognitive or "think-aloud" interviews^[43, 44] with English and French-speaking participants (n=15) living in Montreal in order to examine whether items were understood in the way we intended. All procedures for conducting the cognitive interviews were approved by St. Mary's Hospital, Montreal, Quebec.

3.1. Defining Dimensions of Patient Experiences in PHC

Dimensions of patient experiences in PHC were identified from three main sources. First, Haggerty et al.^[40] proposed 25 different dimensions to consider when assessing the impacts of PHC renewal initiatives. The 25 dimensions are categorized into five groups: clinical practice attributes, practice structural dimensions, person-oriented dimensions, community-oriented dimensions, and system performance dimensions. There are dimensions found to be specific to primary care: accessibility-first contact, continuity-relational, family-centered care, intersectoral team, population orientation. Of the 25 dimensions defined by Haggerty et al., some dimensions relevant to PHC are best measured using patients' reports of their experiences, notably accessibility, continuity, and interpersonal communication.^[40, 42]

Second, our work was informed by the Framework for Primary Care created by Hogg et al.^[45] They developed a conceptual framework designed to support

the measurement of PHC system performance in two complementary domains: structural and performance. "The structural domain describes the health care system, practice context and organization of the practice in which any primary care organization operates. The performance domain includes features of health care service delivery and technical quality of clinical care".^[45, p.398]

Finally, our work was informed by the PHC Logic Model.^[46] This model identifies inputs, outputs, and immediate, intermediate, and final outcomes. The PHC Logic Model outputs rely on the identification of important dimensions of PHC by Haggerty et al.^[40] We specifically drew on the PHC Logic Model immediate outcomes in creating the Patient Experience Survey since increased knowledge about health and health care among the population and reduced risk and effects of continuing conditions "are, for the most part, under the direct control of the PHC sector."^[46, p.7]

Based on our review of these main sources, six dimensions of PHC are important to measure from patients' perspectives:

1. Access
2. Interpersonal Communication
3. Continuity and Coordination
4. Health Promotion within Technical Quality of Care
5. Trust
6. Patient-Reported Impacts of Care.

Each dimension (see Table 1) includes a brief definition. In total, our classification yielded six dimensions and 15 sub-dimensions of patient experiences in PHC.



Table 1: Dimensions of patients’ experiences in primary health care

Dimension	Sub-dimension	Definition
Access	First contact accessibility	The ability to obtain patient-or client-initiated needed care (including advice and support) from the provider of choice within a time frame appropriate to the urgency of the problem. ^[40]
	Accommodation	The relationship between how resources are organized to accept patients or clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the patients’ or clients’ ability to accommodate to these factors to realize access. ^[40]
	Economic accessibility	The extent to which direct or indirect costs related to care impeded decisions to access needed care or continue recommended care.
Interpersonal communication	General communication	The ability of the provider to elicit and understand patient or client concerns, and to explain health and health care issues. ^[40, 47]
	Respectfulness	The ability of the primary care organization and practitioners to provide care that meets the expectations of users about how people should be treated, such as regard for dignity and provision of adequate privacy. ^[40, 47]
	Shared decision-making	The extent to which patients or clients are involved in making decisions about their treatment. ^[47]
	Whole-person care	The extent to which providers address the physical, emotional and social aspects of a patient’s or client’s health and consider the community context in their care. ^[40]
Continuity and coordination	Relational continuity	A therapeutic relationship between a patient or client and one or more identified providers that spans separate health care episodes and delivers care that is consistent with the patient’s or client’s biopsychosocial needs. ^[40]
	Information continuity	The extent to which information is used to make current care appropriate to the patient or client.
	Coordination	The provision and organization of a combination of health services and information with which to meet a patient’s or client’s health needs, including services available from other community health service providers. ^[9, 10]
	Team functioning	The ability of primary health care providers to work effectively as a collaborative team to manage and deliver quality patient or client care.
Comprehensiveness of services	Services provided	The provision, either directly or indirectly, of a full range of services to meet patients’ or clients’ health care needs. This includes health promotion, prevention, diagnosis and treatment of common conditions, referral to other clinicians, management of chronic conditions, rehabilitation, palliative care and, in some models, social services. ^[40]
	Health promotion and primary prevention	Health promotion is the process of enabling people to increase control over, and to improve, their health. ^[12] Primary prevention is directed towards preventing the initial occurrence of a disorder. ^[13]
Trust		An expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation. For example, patient or client trust in the physician provides a basis for taking the risk of sharing personal information. ^[48]
Patient-reported impacts of care	Patient activation	Patient’s or client’s ability or readiness to engage in health behaviors that will maintain or improve their health status. ^[49, 50]
	Patient safety	Patient’s or client’s reports of medication errors (given or taken the wrong drug or dose) or incorrect medical or laboratory reports and communication with their provider about not taking their prescribed medication or medication side effects.
	Confidence in the PHC system	The perception that allows patients or clients of health care to make decisions since they assume (and expect) relative certainty about providers delivering safe and technically competent care. ^[51]

3.2. Identifying Relevant Instruments and Surveys

Relevant instruments and surveys were assessed based on previous work completed by Wong^[52,53] and Haggerty,^[54] an environmental scan of health surveys completed by the CIHI, and a review of the peer-reviewed and grey literature. The literature review focused on material (published and unpublished) available in Canada related to the identification of different dimensions of patient experiences in PHC, as well as on international material (specifically, from Europe, Australia, New Zealand and the United States) that had the potential to be applied in a Canadian setting.

The items identified from the instruments and surveys for inclusion in the Patient Experience Survey were selected based on two criteria:

1. Relevant to patients' experiences in PHC
2. Publicly available.

Instruments and surveys published in English and French were considered for review.

3.3. Classification

Information available from instruments and surveys was entered into a Microsoft Excel data table. For each instrument and survey, a research assistant classified the items within the dimensions of patient experiences in PHC (see Table 1). Once the items were classified, two independent observers (Haggerty & Wong) assessed the relevance of the classification. Tables were then iteratively adjusted until the authors reached consensus with regards to which item should be attributed to each dimension.

The instrument or survey covered at least one item in a dimension in order to obtain a check mark; that is, the number of items from the same instrument or survey within a dimension was not a factor for inclusion in this table.



4. Results

In reviewing the literature, we found many instruments and surveys that assessed patient experiences in PHC. As part of the work for this report, we also reviewed the New Brunswick Patient Health Care Experience Survey,^[55] the Manitoba Physician Integrated Network patient survey,^[56] The Ontario Primary Care Access Survey,^[57] and the Nova Scotia Primary Care Practice Survey.^[58] No items from these surveys were retained since they were mainly based on previously identified instruments (e.g., Primary Care Assessment Tool^[59]). Additionally, several other instruments and surveys were reviewed and informed the final Patient Experience Survey; these included work completed in a number of different countries. Instruments and surveys from Europe included EUROPEP^[60] and Quality and Cost of Primary Care (QUALICO-PC) Patient Experiences and Patient Values questionnaires.^[61] Instruments and surveys from the United States included Components of Primary Care Index,^[33] Patient Satisfaction Questionnaire Short Form (PSQ-18),^[62] VA National Outpatient Customer Satisfaction Survey,^[63] The Consultation Quality Index^[64], Measure of Processes of Care^[65], Patient Experiences Questionnaire^[66], Patient Perception of Patient Centred Care,^[67] Patient Activation Measure Short Form^[49], and Patient Enablement Index.^[68]

We retained a total of 17 instruments and surveys from which items were retained for the final Patient Experience Survey (see Table 2). The instruments varied in size (long or short version) as did the number of dimensions and sub-dimensions (e.g., accessibility, continuity, interpersonal processes of care). Most of them aimed to measure access and continuity of care experiences. The processes of care such as respectfulness of the provider, shared decision-making, and coordination of care were also widely measured by these instruments.

The instruments and surveys varied in length (from 12 questions to more than 250 questions). They also varied as to whether the patient was asked to respond about their most recent visit or about their general experiences in PHC with their usual provider over the last 12 months.

The 17 instruments and surveys were designed to be used mostly in primary care settings; ten were created in a country other than Canada, one was an international initiative (Commonwealth Fund International Health Policy survey) and nine were administered only in Canada. The geographic areas covered by each survey tool varied from one study to another: international (e.g., QUALICO-PC=34 countries, Commonwealth Fund=10 countries), national (e.g., Canadian Survey of Experiences with PHC, General Practice Assessment Questionnaire) and regional (e.g., Accessibilité Rurale II, Interpersonal Processes of Care). All surveys and the majority of studies using these instruments are cross-sectional, collecting data at one point in time.

4.1. Dimensions of Patient Experiences in Primary Health Care Covered by Existing Surveys and Instruments

Table 3 shows the coverage of patient experiences in PHC dimensions by the surveys and instruments. No one survey or instrument covered the entire range of patient experience in PHC dimensions.

Table 2: Retained surveys and instruments from which the patient experience survey was developed

Origin	Name of the survey / project	Acronym	# Items retained for pt. experience survey***
Canada	Canadian Survey of Experiences with Primary Health Care, 2007 ^[69]	CSE-PHC 2007	3
	Canadian Community Health Survey ^[36]	CCHS	11
	Accessibilité Rurale II ^[70]		6
Québec (Canada)	RuralII ^[71]		
	Questionnaire populationnelle ^[72]	QPop	1
	Management Continuity ^[73]		17
British Columbia (Canada)	*Patient Experiences in Primary Care in BC ^[53] / Patient Experiences in Primary Care: BC, Manitoba, and Quebec ^[52]		13
United Kingdom	**National Health Service Patient Survey ^[74]	NHS patient survey	8
	General Practice Assessment Survey ^[75]	GPAS	4
	General Practice Assessment Questionnaire ^[76]	GPAQ	11
United States	Consumer Assessment of Health Plan Survey clinician and group survey, 2011 ^[77]	CAHPS	1
	Interpersonal Processes of Care original and short form ^(47, 78)	IPC	17
	Primary Care Assessment Tool ^[79]	PCAT	3
	Primary Care Assessment Survey, Ambulatory Care Experiences Survey ^[29,80]	PCAS/ACES	4
	Patient Assessment of Care for Chronic Conditions ^[81]	PACIC	4
	Commonwealth Fund International Health Policy Survey ^[82]	CWF	3

* Three questions on patient activation in the Patient Experiences surveys were informed by Hibbard et al's^[49] work.

** Several annual versions of the NHS patient survey were reviewed. Seven items on the CIHI Patient Experience survey showed up in more than one survey (questions 3, 4, 5, 6, 18, 19, and 20).

*** One question in the Dimension of Patient Reported Impacts of Care was created during this process: "In the last 12 months, have you taken the wrong medication or wrong dose that was prescribed to you by a doctor, nurse, or pharmacist? Responses: Yes, No, not that I know of"



Table 3: Summary of the classification of the survey and instruments

	CSE-PHC	Accessibilité Rurale II/III	QPop	Management Continuity	Patient Experiences in PHC: BC/BC, Manitoba, Quebec	NHS Patient Survey	GPAS	GPAQ	CAHPS	IPC	PCAT	PCAS/ACES	PACIC	CWF
Access														
First contact accessibility	x	x	x		x	x	x	x	x		x	x		x
Accommodation	x	x	x	x	x	x	x	x	x			x		x
Economic accessibility	x	x	x		x									x
Interpersonal communication														
General communication	x		x	x	x	x	x	x	x	x		x	x	x
Respectfulness			x		x	x		x	x	x		x	x	
Shared decision-making	x				x	x		x		x			x	x
Whole-person care	x		x	x	x	x	x		x	x	x	x	x	x
Continuity and coordination														
Relational continuity	x		x	x	x		x	x	x		x	x	x	x
Information continuity	x		x	x			x				x	x		
Coordination	x		x	x	x		x				x	x	x	x
Team functioning	x		x	x	x		x				x	x	x	
Comprehensiveness of services														
Services provided	x			x	x	x	x				x			x
Health promotion and primary prevention	x		x	x	x		x			x	x	x	x	x
Trust														
				x		x	x	x		x		x		
Patient-reported impacts of PHC														
Patient activation	x				x					x			x	x
Patient safety	x									x	x		x	x
Confidence in the PHC system				x	x									x

Note: The Canadian Community Health Survey (CCHS) is not included here since the items obtained were sociodemographic questions only.

5. Discussion

5.1. Instruments and Surveys Selected

Many instruments and surveys assessed patient experiences relevant to PHC. The majority of instruments and surveys were administered face-to-face or over the telephone. All instruments and surveys were available in English, with fewer being available in English and French. As mentioned above, some instruments and surveys offered better coverage than others. The majority of instruments and surveys did not include known patient reported outcome measures such as functional and emotional health status.

This work highlights the fact that many instruments and surveys exist to assess patient experiences in PHC. While most dimensions of PHC that are best reported by patients are covered by existing tools, certain dimensions about the quality of care remain under-developed. For example, the dimensions of: coordination, trust with provider and the practice, and team functioning could be further developed to more fully capture patients' reports of these experiences. These dimensions are important aspects of patients' care that can influence their health status and use of health services.

No single instrument or survey will likely offer the full coverage of patient experience dimensions relevant to PHC. The review of instruments and surveys helps clarify the dimensions which are measured by each item that in turn will facilitate the selection of the questions depending on the research aim. This review could be useful to those intending to measure multiple dimensions of patient experiences in PHC.

5.2. The Patient Experiences Survey

The instrument and survey items identified in this review informed the content of the Patient Experiences Survey. We attempted to cover all dimensions of care that can be accurately and precisely measured by patient reports and ratings. There are a total of six dimensions of care captured with the Patient Experiences Survey: Access, Interpersonal Communication, Continuity and Coordination, Comprehensiveness of Services, Trust, and Patient-Reported Impacts of PHC. These dimensions cover outputs and immediate outcomes of PHC that are best reported by patients. The immediate outcomes of PHC are considered patient-reported impacts of PHC delivery.

The majority of dimensions include between two and four sub-dimensions. For example, within the dimension of Interpersonal Communication there are four sub-dimensions: General Communication, Respectfulness, Shared Decision-Making, and Whole-Person Care. Several items (n=20) are provided to measure these four sub-dimensions. The number of items used to measure the various dimensions and sub-dimensions of patient experiences may seem daunting. The length of the survey administered to patients will depend ultimately on the dimension and sub-dimension of interest and the purpose for which the survey is being conducted. Therefore, choosing dimensions and sub-dimensions of interest, rather than specific items, should be identified at the beginning of the survey process as the time needed to complete the survey can impact costs and response rates. We suggest that these dimensions and sub-dimensions capture various aspects of how the PHC system is performing.



For the various items, we often adapted questions and/or response options to ensure that the survey was coherent and that there was consistency in the reference or frame used. In various instances, we had conducted research that allowed us to determine more suitable response options.^[83-86] The Patient Experiences Survey captures both patients' reports of their experiences immediately following their visit and also their experiences in PHC over the past 12 months. Although cognitive interviewing has informed the construction of the Patient Experiences Survey, planned validation of the instrument will provide insight into items that measure common underlying constructs (which we expect to correspond to attributes of care) and whether there are places for item reduction with little impact on construct validity.

5.3. Limitations and Strengths

In building our summary of the classification of items found in the instruments and surveys, we were limited in assessing the appropriate coverage of various dimensions/sub-dimensions as we resorted to a simple covered/not covered dichotomy. Further research would be necessary to analyze the depth in which each dimension is covered by each survey or instrument selected. Further, an overall assessment of how well the instruments and surveys perform amongst various groups (e.g., men vs. women, older adults with multiple chronic conditions, those who are marginalized by multiple intersecting determinants of health) was not performed. Our intent was solely to map the surveys and instruments to a set of attributes seen as important in evaluating PHC performance from patients' perspectives. Finally, we did not perform an in-depth analysis of the reliability or validity of the

different instruments and surveys. The Patient Experience Survey did undergo cognitive testing in English and French to assess whether the item was interpreted as intended by patients. Content validation of our survey was assessed by garnering feedback from the larger PHC research community.

This work was aimed at identifying the relevant dimensions of PHC best measured through patient reports. However, we cannot be sure that we have captured all available and relevant surveys and instruments. While we are confident that our review of surveys and instruments captured the most used tools, it could be that there are dimensions of PHC best captured through patient reports that were missed. One example is how the dimension of Equity, the extent to which access to health care and quality services are provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics^[40], is not measured by the Patient Experiences Survey. Work is currently underway by Browne, Varcoe, and Ford-Gilboe^[87] to construct and pilot test questions that will capture the dimension of Equity from patients.

6. Conclusion

To support current measurement of patient experiences in PHC, it is important that health providers, managers, patients and decision-makers have access to a greater number of convincing and comparable data (existing and new). The number of dimensions of PHC best reported by patients, as we have seen in the work of Haggerty et al.^[40] Hogg et al.,^[45] and Watson et al.,^[46] suggest that conceptualizing patient experiences is complex. Many dimensions were considered for the final Canadian Patient Experiences Survey. This work documented and classified existing patient experiences in PHC surveys and instruments and also provided the foundation for the development of the Canadian Patient Experiences Survey. The final survey consists of six dimensions of PHC best measured from patient reports of their experiences.



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8. Appendix

8.1. Classification of the Items from the Selected Survey Tools

This appendix presents the PHC patient experience survey items and responses related to the review of selected surveys. The questions are grouped according to the dimensions of patient experiences in PHC presented in Table 3.

8.2. Access

8.2.1. First contact accessibility: The ability to obtain patient- or client-initiated needed care (including advice and support) from the provider of choice within a time frame appropriate to the urgency of the problem.

Instrument	Question	Item stem	Response categories
Rural I/III	Q21	Based on your experience, how easy is it for you to get health advice from your clinic over the phone?	Not at all easy / Not very easy / A bit easy / Moderately easy / Very easy

8.2.2. Accommodation: The relationship between how resources are organized to accept clients or patients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' or patients' ability to accommodate to these factors to realize access.

Instrument	Question	Item stem	Response categories
Patient Experiences	Q1	Why did you come to the clinic today? (Check all that apply)	Routine examination / Follow-up of a health problem/pregnancy follow-up / New health problem / An urgent but minor health problem / Prescription renewal / Many issues to discuss / Other, specify_____
Patient Experiences	Q2	How long did you wait between making this appointment and your visit today?	I had a walk-in appointment -> Go to question 5 1 to 2 days / Between 2 days and 1 week / 1 to 2 weeks / 2 to 4 weeks / 4 to 6 weeks / More than 6 weeks
GPAQ & NHS	Q3	How do you rate this wait?	Not acceptable at all / Not very acceptable / Moderately acceptable / Acceptable / Very acceptable
GPAQ & NHS	Q4	How easy was it to make this appointment?	Very easy / Fairly easy / Not very easy / Not at all easy
GPAQ & NHS	Q5	How easy was it to get through to someone at your clinic on the phone?	Very easy / Fairly easy / Not very easy / Not at all easy / Not applicable
GPAQ & NHS	Q6	How long did you wait for your consultation to start?	Less than 5 minutes / 5 to 10 minutes / 11 to 20 minutes / 21 to 30 minutes / More than 30 minutes / There was no set time for my consultation No -> Go to question 21 / Yes, once -> / Yes, several times ->
CSE-PHC & Patient Experiences	Q20	Were there times when you had difficulty getting the healthcare or advice you needed?	If yes, what type of difficulties did you experience? Difficulty contacting a physician / A specialist was unavailable / Difficulty getting an appointment / Do not have personal/family physician / Waited too long to get an appointment / Waited too long in the waiting room / Service not available at time required / Service not available in the area / Transportation problems / Cost issues / Language barriers / Did not feel comfortable with the available doctor or nurse / Did not know where to go (i.e., information problems) / Unable to leave the house because of a health problem / Other, please specify: _____

8.2.3. Economic Accessibility: The extent to which direct or indirect costs related to care impeded decisions to access needed care or continue recommended care.

Instrument	Question	Item stem	Response categories
			No / Yes ->
QPop	Q22	<i>Thinking about costs related to your healthcare...</i> In the past year, did you ever pay directly for any services in your doctor's office?	If yes, was it: Opening a file / Filling in forms / Getting a sick note / Medical services not covered by Medicare / Medicine or shots / Administration costs, please specify: _____
Rural II/III	Q23-27	<i>In the past year...</i> 23. Were there times when you did not take medicines prescribed by a doctor because of their costs? 24. Were there times when you did not take laboratory tests or exams because of their costs? 25. Were there times when you did not get services recommended by your doctor that aren't covered by health insurance because of their costs? (such as physiotherapy, psychotherapy, dietetic...) 26. Were there times when you found it difficult to get health care because you had to take time off work? 27. Were there times when you found it difficult to get health care services because of the additional costs it involves? (babysitting, parking, etc.)	Never / Rarely / Sometimes / Often / Very often / I don't take any drugs Never / Rarely / Sometimes / Often / Very often / I did not use any of these services

8.3. Interpersonal Communication

8.3.1. General communication: The ability of the provider to elicit and understand patient or client concerns, and to explain health and health care issues.

Instrument	Question	Item stem	Response categories
GPAQ	Q8-11	<i>Thinking about your visit today...</i> 8. How would you evaluate the amount of time that the person gave you? 9. How would you evaluate the way they listened to you during the visit? 10. How would you evaluate their explanations of tests and treatments? 11. How would you evaluate the way they involved you in decisions about your care?	Very good / Good / Fair / Poor / Very poor
IPC	Q12-15	<i>Still thinking about the person you saw during your visit today...</i> 12. Did he or she really find out what your concerns were? 13. Did he or she let you say what you thought was important? 14. Did he or she take your health concerns very seriously? 15. Was he or she concerned about your feelings?	Yes, completely / Yes, mostly / Yes, a little / No, not really / No, not at all
CWF	Q16-17	<i>Still thinking about the person you saw during your visit today...</i> 16. Did he or she give you clear instructions about symptoms to watch for and when to seek further care or treatment? 17. Did he or she discuss with you your main goals or priorities in caring for your condition?	Yes, completely / Yes, mostly / Yes, a little / No, not really / No, not at all



8.3.2. Respectfulness: The ability of the primary care organization and practitioners to provide care that meets the expectations of users about how people should be treated, such as regard for dignity and provision of adequate privacy.

Instrument	Question	Item stem	Response categories
GPAQ	Q28	<i>Over the past 12 months...</i> How helpful did you find the receptionist at your clinic?	Very helpful / Moderately helpful / Somewhat helpful / Not at all helpful
CAHPS	Q29	<i>Over the past 12 months...</i> Did the clerks and receptionists at this clinic treat you with courtesy and respect?	Never / Sometimes / Often

8.3.3. Shared decision-making: The extent to which patients are involved in making decisions about their treatment.

Instrument	Question	Item stem	Response categories
IPC	Q31-34	<i>Over the past 12 months...</i> 31. Did you and your doctor work out a treatment plan together? 32. Did your doctor ask you questions about your daily activities before deciding a treatment plan? 33. Did your doctor ask if you felt you could do the recommended treatment plan? 34. When there were treatment choices, did your doctor ask you what treatment you would prefer?	No / Yes, sometimes / Yes, often / I don't receive any treatment
PACIC	Q64	<i>Over the past 6 months...</i> 64. When you received care for your chronic conditions were you helped to make a treatment plan that you could carry out in your daily life?	Yes, certainly / Yes, probably / Maybe, not sure / No, not really / No, not at all / No, I haven't needed such support

8.3.4. Whole-person care: The extent to which providers address the physical, emotional and social aspects of a patient's or client's health and consider the community context in their care.

Instrument	Question	Item stem	Response categories
Management Continuity/ PCAS / ACES	Q35-38	<i>About your visits to your doctor/clinic over the past 12 months...</i> 35. Did your doctor or nurse seem to know about your whole medical history? 36. Did your doctor or nurse seem to know about what worries you most about your health? 37. Did your doctor or nurse seem to know about your responsibilities at work or home? 38. Did your doctor or nurse seem to know about your personal values?	Hardly at all / A little / Moderately / A lot / Totally

8.4. Continuity and Coordination

8.4.1. Relational continuity: A therapeutic relationship between a patient or client and one or more identified providers that spans separate health care episodes and delivers care that is consistent with the patient’s or client’s biopsychosocial needs.

Instrument	Question	Item stem	Response categories
PCAT	Q7	Is there a person (health professional) who knows you best at this clinic?	No -> Go to question 8 / Yes
			If yes, is this a... A family doctor or general practitioner / A nurse practitioner / A specialist / A nurse / Some other health professional (please specify)_____
			Did you see this person today? Yes / No
			Would you say this person is responsible for most of your health care? Yes / No
PCAT	Q30	Thinking of the past 12 months, when you went to this clinic, how often were you taken care of by the same person?	Always / Usually / Sometimes / Rarely / Never

8.4.2. Information continuity: The extent to which information is used to make current care appropriate to the patient or client.

Instrument	Question	Item stem	Response categories
Management Continuity	Q39-43	<p>About ALL the different people that you saw at ALL the different places you got care over the last year</p> <p><i>Over the past 12 months...</i></p> <p>39. Were there times when the person you were consulting did not know your most recent medical history?</p> <p>40. Were there times when the person you were seeing did not have access to your recent tests or exam results?</p> <p>41. Were there times when you had to repeat tests because the person you were seeing did not have access to results?</p> <p>42. Were there times when the person you were seeing did not know about changes in your treatment that another person recommended?</p> <p>43. Were there times when you had to repeat information that should be in your medical record?</p>	Never / Rarely / Sometimes / Often / All the time



8.4.3. Coordination: The provision and organization of a combination of health services and information with which to meet a patient’s or client’s health needs, including services available from other community health service providers.

Instrument	Question	Item stem	Response categories
Management Continuity	Q46	<p>About your experiences with any kind of care outside the clinic <i>Over the past 12 months...</i> In general, do you feel that you yourself have to arrange the healthcare you receive from different persons or places?</p>	<p>No, the person who follows my care always does it for me / No, the person who follows my care sometimes does it for me / Yes, but it is my choice to do so / Yes, I have to organize my care more than I would like / Yes, too much and it is too difficult</p>
Management Continuity	Q47	<p>About your experiences with any kind of care outside the clinic <i>Over the past 12 months...</i> Thinking about all the different persons you saw in all the places you went for care; Is there ONE person who ensures follow-up of your healthcare?</p>	<p>No -> Go to question 47 / Yes</p> <p>If yes, is this person a: A nurse / A nurse practitioner / Your doctor / Other health professional, please specify: _____</p> <p>How much does this person keep in contact with you even when you receive care in other places? Not at all / Very little / Moderately / Quite a lot / A lot</p> <p>How much does this person help you get the health care you need from other places? Not at all / Very little / Moderately / Quite a lot / A lot</p> <p>How much does this person contact other health professionals about your care? Not at all / Very little / Moderately / Quite a lot / A lot</p>
Management Continuity	Q69-71	<p>About the person whom you see most at this clinic. <i>Over the past 12 months...</i> 69. How much importance does this person give to your ideas about your care? 70. How comfortable do you feel talking with this person about personal problems related to your health condition? 71. How confident are you that this person will look after you no matter what happens with your health?</p>	<p>Hardly any importance / Only a little / Moderate importance / A lot of importance / Immense importance</p> <p>Hardly comfortable at all / Only somewhat / Moderately / Very comfortable / Completely comfortable</p> <p>Not very confident at all / Only somewhat / Moderately / Very confident / Completely confident</p>
PACIC	Q63	<p><i>Over the past 6 months...</i> 63. When you received care for your chronic conditions were you encouraged to go to a specific group or class to help you cope with your chronic condition?</p>	<p>Yes, certainly / Yes, probably / Maybe, not sure / No, not really / No, not at all / No, I haven't needed such support</p>
PACIC	Q65-66	<p><i>Over the past 6 months...</i> 65. When you received care for your chronic conditions were you contacted after a visit to see how things were going? 66. When you received care for your chronic conditions were you encouraged to attend programs in the community that could help you?</p>	<p>Yes, certainly / Yes, probably / Maybe, not sure / No, not really / No, not at all / No, I haven't needed such support</p>

8.4.4. Team functioning: The ability of primary health care providers to work effectively as a collaborative team to manage and deliver quality patient or client care.

Instrument	Question	Item stem	Response categories
Management Continuity	Q48-50	<p>About all the people working at the clinic where your regular doctor see you</p> <p>48. Were there times when persons from your clinic told you different things (that didn't make sense together) about your health?</p> <p>49. Were there times when persons from your clinic did not seem to work well together?</p> <p>50. Were there times when persons from your clinic did not seem to know who should be doing what in your healthcare?</p>	Never / Sometimes / Often
Patient Experiences	Q67-68	<p>67. Other than your doctor, who else at your clinic do you see to manage your health condition? (Check as many as apply)</p> <p>68. Other than people at this clinic, who else do you see to manage your health condition?</p>	Only my usual doctor / Other family doctor or general practitioner / A specialist / A nurse / A nurse practitioner / A nutritionist or a dietician / A physiotherapist or an occupational therapist / A psychologist or a social worker / complementary/alternative person (e.g., acupuncturist, chiropractor, registered massage therapist, etc.) Please specify _____ / Other, please specify _____

8.5. Comprehensiveness of Services

8.5.1. Services provided: The type and range of services delivered by primary health care providers. This also includes referrals to and from the primary health care organization.

Instrument	Question	Item stem	Response categories
NHS	Q51-52	<p>About the care you receive</p> <p>51. In the last 12 months, has your clinic provided everything you need to help you manage your health concerns?</p> <p>52. In the last 12 months, have you had enough support from local services or organizations to help you manage your health concerns?</p>	Yes, definitely / Yes, to some extent / No, not really / No, not at all / No, I haven't needed such support

8.5.2. Health promotion and primary prevention: Health promotion is the process of enabling people to increase control over, and to improve, their health. Primary prevention is directed towards preventing the initial occurrence of a disorder.

Instrument	Question	Item stem	Response categories				
			Your doctor	Another doctor	A nurse	Some-one else (specify)	No one
PCAT	Q53	Over the past year, who at this clinic talked to you about any of the following subjects? Check as many as apply for each subject					
			Impact of healthy and non-healthy foods on your health				
			Importance of healthy weight				
			Importance of exercise/ healthy lifestyle				
			Tobacco use on your health				
			Alcohol or drug use				
			Prevention of falls				
			Ways to handle family conflicts that may arise from time to time				
			Prevention of risks at work				



8.6. Patient Reported Impacts of Primary Health Care

8.6.1. Patient activation: People’s ability or readiness to engage in health behaviors that will maintain or improve their health status.

Instrument	Question	Item stem	Response categories
IPC	Q54-58	<i>Over the past 12 months...</i> 54. Did the person you saw most at the clinic help you feel that your everyday activities such as diet and lifestyle would make a difference in your health? 55. Did the person you saw most at the clinic help you feel that you could prevent some health problems? 56. Did the person you saw most at the clinic give you a sense of control over your health? 57. Did the person you saw most at the clinic help you feel that sticking with your treatment would make a difference? 58. Did the person you saw most at the clinic help you feel confident about your ability to take care of your health?	Yes, definitely / Yes, to some extent / No, not really / No, not at all
		About you and your health 59. How well do you understand the nature and causes of your health problems? 60. How well do you know how to prevent problems with your health? 61. How confident are you that you can maintain the changes in your health habits like diet and exercise, even during times of stress? 62. Has any health professional ever diagnosed you with or treated you for any of the following chronic health conditions? Check as many as apply.	Completely / Very well / Moderately / A little / Hardly at all / I don't have any health problems Totally confident / Very well / Moderately / A little / Hardly confident at all Heart disease / Arthritis or Rheumatoid Arthritis / High blood pressure or Hypertension / Depression or Anxiety / Diabetes / Other chronic health problems

8.6.2. Patient safety: Patients’ or clients’ reports of medication errors (given or taken the wrong drug or dose) or incorrect medical or laboratory reports and communication with their provider about not taking their prescribed medication or medication side effects.

Instrument	Question	Item stem	Response categories
IPC	Q44-45	<i>Over the past 12 months...</i> 44. How often did doctor(s) tell(s) you about side effects you might get from a medicine? 45. How often did doctor(s) tell(s) you what could happen if you don't take the medicine they prescribe for you?	Never / Rarely / Sometimes / Often / All the time
Patient Experiences	Q84-85	84. In the last 12 months, have you been given the wrong medication or wrong dose by a doctor, nurse, or pharmacist? 85. In the last 12 months, have you been given incorrect results for a diagnostic or lab test?	Yes / No, not that I know of

8.6.3. Confidence in the PHC system: The perception that allows patients to make decisions since we assume (and expect) relative certainty about providers delivering safe and technically competent care.

Instrument	Question	Item stem	Response categories
Patient Experiences	Q86-87	86. On a scale of 0-10, how confident are you that you could get the primary healthcare services you need? *Primary healthcare services are the ones we usually receive in clinics, doctor's office or CLSC-not the emergency room of a hospital 87. On a scale of 0-10, how confident are you in your provincial healthcare system?	Not at all confident -> Totally confident 0 / 1 / 2 / 3 / 4 / 5 / 6 / 7 / 8 / 9 / 10

8.7. Trust

An expectation that the other person will behave in a way that is beneficial and that allows for risks to be taken based on this expectation. For example, patient trust in the physician provides a basis for taking the risk of sharing personal information.

Instrument	Question	Item stem	Response categories
GPAQ & NHS	Q18	<i>Thinking about your visit today...</i> Did you have confidence in the doctor you saw or spoke to?	Yes, definitely / Yes, to some extent / No, not at all No -> Go to question 20 / Yes ->
GPAQ & NHS	Q19	<i>Thinking about your visit today...</i> Did you speak to any other health care professional at the clinic today?	Please specify: Check as many as apply Only my usual doctor / Other family doctor or general practitioner / A specialist / A nurse / A nurse practitioner / A nutritionist or a dietician / A physiotherapist or an occupational therapist / A psychologist or a social worker / Complementary/Alternative person (e.g., acupuncturist, chiropractor, registered massage therapist, etc) please specify ____ / Other, please specify _____ Did you have confidence in this other person you saw or spoke to? Yes, definitely / Yes, to some extent / No, not at all



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